

EVERY. HOUR. COUNTS.

Webinar to Launch the
Statewide Collaborative Initiative to Improve Timeliness in
Blood Spot Newborn Screening



Presenters

- Ashley Comer, Clinical Lab Analyst, Newborn Screening Laboratory
- Carol Johnson, Iowa Newborn Screening Follow Up Coordinator
- Kimberly Noble Piper, Executive Officer, Center for Congenital and Inherited Disorders, State Genetics Coordinator, Iowa Department of Public Health

Disclosure

This project is funded by the Health Resources and Services Administration (HRSA) and the Association of Public Health Laboratories (APHL) to the Iowa Newborn Screening Program

Collaboration



And YOU!!!!

Educational Objectives

- Describe the importance of timely newborn screening, and identify the timeliness goal for Iowa
- Recall procedure for submitting dried blood spot collection forms to the State Hygienic Lab (SHL)
- Verbalize understanding of Iowa laws pertaining to newborn screening
- Use the newborn screening infographic for their facility to improve timeliness of newborn screening

Background

- Newborn Screening celebrated 50th Anniversary in 2013
- Investigative Report by Milwaukee Journal Sentinel in November 2013 exposed “Deadly Delays” in NBS
- Problem: “Time-Critical” conditions included in state NBS Programs.
- Solution: Enhanced structures and processes

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Each of these bullets I thought could be discussed briefly to give an overview of the state of NBS and “timeliness” as it exists today. This leads to the development of the Timeliness recommendations developed by the ACHDNC.

MSJ Article Link: <<http://www.jsonline.com/watchdog/Deadly-Delays-Watchdog-Report-newborn-screening-program-231927171.html>>

ACHDNC Recommendations

1. Presumptive positive results for time-critical conditions should immediately be reported to the child's healthcare provider (and no later than 5 days of life).
2. All presumptive positive results for time sensitive conditions should be reported to the healthcare provider as soon as possible but no later than 7 days of life.
3. All NBS results should be reported within 7 days of life (the "normal" screening results).
4. In order to achieve these goals (and reduce delays in newborn screening):
 - Initial NBS specimens should be collected in the appropriate time frame for the baby's condition but no later than 48 hours after birth.
 - NBS specimens should be received at the Laboratory as soon as possible; ideally within 24 hours of collection.

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The MSJ led to national attention resulting in the ACHDNC developing recommendations for "Timeliness" (given the time-critical conditions on the RUSP). Brief description of ACHDNC: The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) was chartered in 2003, and held its first meeting in 2004. The charter tasked the SACHDNC with advising the HHS Secretary on activities and developments that reduce morbidity or mortality of newborns and children with or at risk for heritable disorders. In 2006, the SACHDNC endorsed the ACMG recommendation for the RUSP (the RUSP, Recommended Uniform Screening Panel, is a set of conditions reviewed by the ACHDNC and recommended by the Secretary of the Department of Health and Human Services as a minimum standard for mandated state universal newborn screening programs. It is the prerogative of each state to adopt the RUSP.

Realities

- Babies are born with “Time-Critical” conditions that if not discovered in time and effective interventions initiated will suffer harm and may experience a metabolic crisis leading to coma and possibly death.
- Babies with these conditions can be born on any day of the week.

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These were the “realities” that led the CIDAC to request a proposal from the NBS Program (me specifically) to address the recognized realities to reduce the “risk of harm” for Iowa babies.

These realities led to the desired outcomes presented in the next slide.

Desired Outcomes

- Specimens must be collected every day
- Specimens must be transported every day
- Specimens must be tested every day
- Presumptive Positive results for Time-Critical conditions must be reported every day
- Appropriate information must be able to be provided to the baby's PCP every day
- So that a baby Presumptive Positive for a Time-Critical condition can be evaluated on any given day.

Every baby **deserves** the same opportunity for a healthy life regardless of which day they are born.

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These were our desired outcomes as we put the proposal together. If possible, we wanted to make the day of the week a child was born irrelevant.

Iowa's Infrastructure

- Dedicated same-day courier picks up NBS specimens every day
- The specimens are picked up every day in the afternoon to early evening and delivered by about 9:30pm that same day.
- The laboratory night shift staff is present every day to receive the specimens and begin testing right away and through the night.
- The laboratory day shift staff is present every day to continue the testing and report results to Program Follow-up staff every day.
- The Program Follow-up staff are available every day to ensure a baby at risk for a time-critical condition is tracked down and can be assessed that same day to determine the need for appropriate interventions.

So that: Every baby has the same opportunity for a healthy life regardless of which day they are born.

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This is what we proposed and put in place.

Challenge

Utilize the available infrastructures as effectively as possible to maximize the benefits of “Timeliness” for all newborns in Iowa.

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What we didn't do as fully as needed, was to make sure everyone in the NBS “System” understood what had changed, what risks came with the changes and enlist them in helping to improve timeliness. Many in the NBS system were not aware of the WHY there was the need for new timeliness requirements. And because of no feedback to the contrary, many at the hospitals assumed they were doing just fine. We want to provide the resources to assist each hospital to be as “timely” as possible.

THUS the CoIN Project...

Iowa CoIIN Project

Goal: 95% of newborn screening specimens will be received at the State Hygienic Laboratory (in Ankeny, IA) within 60 hours from birth.

Newborn Screening Laws

- Two types of law that authorize newborn screening – Iowa Code 136A, and Iowa Administrative Code 641 IAC 4 (also known as administrative rules).
- Code gives authority to screen, and rules describe how the screening will be conducted.

Summary of 641 IAC 4

- Provides definitions, e.g., “attending health care provider” and “primary health care provider”
- Describes the Iowa Newborn Screening Program (INSP):
 - “All newborns and infants born in the state of Iowa shall be screening for all congenital and inherited disorders specified by the center and approved by the state board of health.”
- Newborn blood spot screening procedure for facilities and providers
 - “Before a specimen from the infant is obtained, a parent or guardian shall be informed of the type of specimen, how it is obtained, the nature of the disorders for which the infant is being screened, the consequences of treatment and nontreatment, and the retention, use and disposition of the residual specimens.”
 - Refusal of screening
 - Submission of specimens. “All specimens shall be delivered via courier service or, if courier service is not available, forwarded by first-class mail or other appropriate means within 24 hours after collection to the SHL.”

Summary of 641 IAC 4 (cont.)

- Primary health care provider responsibility.
 - “The health care provider shall ensure that infants under the provider’s care are screened.”
- Birthing Facility.
 - “Designee. Each birthing facility shall designate an employee to be responsible for the newborn screening program in that institution.”
 - “Notification. The birthing facility shall report the newborn screening results to the health care provider who has undertaken ongoing primary pediatric care of the infant.”

Why Do NBS and What is a Time Critical Disorder?

- Tests are performed to detect life threatening and/or life altering conditions which - if detected early -could save a life and/or improve the quality of life for the babies we all take care of
- Time critical disorders are those inherited conditions that require immediate intervention to prevent death, such as galactosemia, congenital hypothyroidism, congenital adrenal hyperplasia and other metabolic disorders...

EVERY HOUR COUNTS

Iowa Neonatal Metabolic Screening Form									
First Screen		Repeat Screen		Check if Infant is a MCHU		Collector's Initials		Infant's Chart Number	
Infant's Last Name				Birth Date (MM/DD)		Day		Year	
Infant's First Name				Sex		Collection Date (MM/DD)		Collection Time (24 hour clock)	
Multiple Births				Current Weight (KG)		Transfusion ABY blood products		Date, Date of Intubation	
<input type="checkbox"/> Yes <input type="checkbox"/> No 1, 2, 3, etc.				<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No		Gestational Age	
Mother's Last Name				Mother's Birth Date (MM/DD)		Day		Year	
Mother's First Name				Mother's Zip Code					
Mother's Phone Number or Contact's Phone Number				Area Code					
Submitting Facility's Name				Facility Number		Submitting Facility's Phone Number			
Submitting Facility's Address				City		State		Zip Code	
Attending Health Care Provider				DO NOT WRITE IN THIS SPACE					
Attending Health Care Provider Phone Number				Area Code					

INMSP LAB COPY

Feeding Method
☐ Formula
☐ Breast
☐ WFO
☐ Parenteral Nutrition
☐ Other

INMSP USE ONLY

Whitman 9039 ☐ W001 XXXXXXXX
 Completely Fill All Circles With Blood From Reverse Side
 ALLOW TO AIR DRY FOR ABOUT 3 HOURS
 DO NOT HEAT



Every time you fill out a newborn screening form you hold a baby's life in your hands.

Fill out the form

- ✓ Accurately
- ✓ Completely
- ✓ Legibly

If the test comes back presumptive positive, the information you provide is essential to locate the baby and the provider. It can be a matter of life and death.

It's not just a form – it's a baby.

Collection of Sample

- Preferred site of collection is the heel
- If the heel is not possible, such as in premature babies, you can use the umbilical catheter. Make sure to clear 2.0-2.5 cc's prior to collecting the NBS sample.
- Capillary tubes – discouraged due to high chance of scratching/contaminating the card
- No venipuncture – blood clots too soon

Early Collection

- **Early Collection (<24 hrs) affects amino acid and endocrine results – invalid – no results reported**
- **BUT – we recommend you collect < 24 hrs if the baby is not doing well, prior to transfusion, if baby will be transferred, or if a baby is going home prior to 24 hrs**
- **Note – babies get missed when transfers occur**

Unintended Consequences of a Poor Quality Sample

- Delays follow up and diagnosis of disorders
- Escalates parent anxiety, negative feelings towards NBS
- Increases the chance that a baby will not receive a valid screen – 28 babies did not get a valid screen in 2014 because the parents didn't bring the baby in to obtain a repeat screen

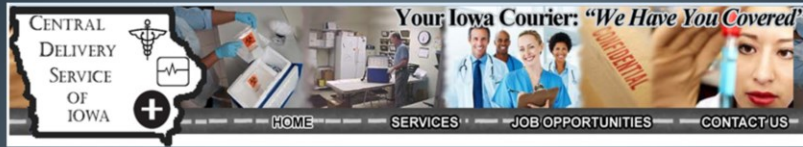
NBS Works 365 Days/Year

- The courier, the NBS lab, and NBS follow up staff work 365 days a year.
- Iowa's NBS program is #1 for timeliness in the country – and you're a part of that
- Only *time critical results* are called out on weekends and holidays

Olivia's Story

- Olivia was eligible to have her NBS collected at noon. It was collected as ordered at 4:00 pm with PM labs.
- Sample was collected with no complications, but had not dried for 3 hours when the courier came to pick up the NBS samples.
- The sample was picked up by the courier the next day and testing began that night by the NBS Lab.
- Meanwhile, Olivia became very ill and had to be admitted to the PICU. It was unclear what was wrong until the NBS result was available the following morning when follow up staff called the PCP with the results of the screen.
- Olivia's screen was presumptive positive for galactosemia. Once proper interventions were done, Olivia improved but has intellectual disability because early intervention didn't occur.

EVERY. HOUR. COUNTS.

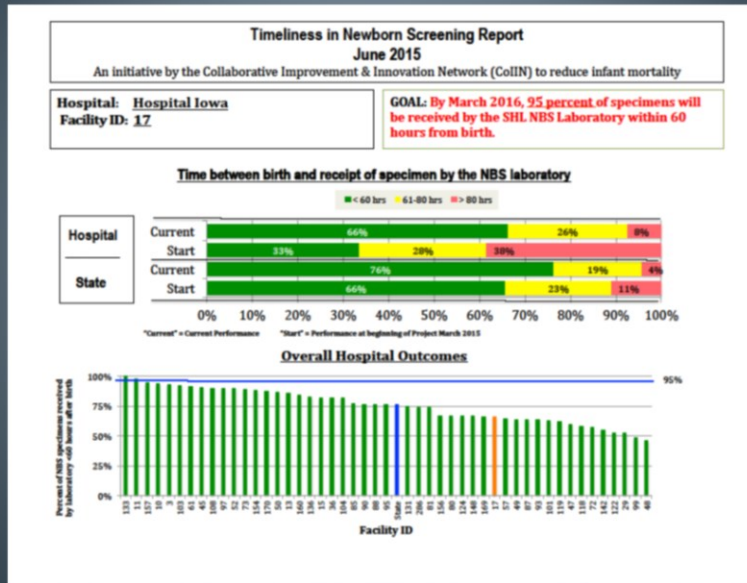


- Courier: Central Delivery Service of Iowa (C.D.S.)
 - www.cdsofiowa.com
 - Same Day service provided 365 days/year
 - Place orders via website by 12:00pm for guaranteed pick-up *that day* and delivery *that night* to SHL.
- Weekend and Holiday pick-ups are business as usual.
 - CDS realizes the importance of Newborn Screening and is driven to help us achieve the most timeliness results for all babies EVERY day.
- Is your facility using the courier appropriately?
 - Are specimens sent on the courier ASAP?
 - All screens collected and dried for 3 hours should be picked up by the courier each day (all 7 days, holidays, and weekends) to avoid delays in testing and possible intervention.
 - Send samples at the first opportunity. Collect sample in time for it to dry, be transported to lab or other internal practices, and processed by send-out departments in time to make daily courier pick-up.
- Any questions, please feel free to contact us.
- Courier Liaison at SHL for Newborn Screening: Ashley Comer
 - ashley-comer@uiowa.edu or 515-725-1630

Resources

- Infographic
- Data
- SHL web portal
- Listserve
- INSP staff
- CoIIN Team
- Each other

Infographic



Data

The State Hygienic Lab web portal provides access to many data reports.

Established reports available include

- Patient lookup
- Samples received
- Quality control
- Turnaround statistics (most useful for ColIN initiative)
- Facility summary
- Facility QA Report

You can also contact one of the state newborn screening staff to request custom data.

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SHL Web Portal for NBS

www.shl.uiowa.edu

RT Authentication Employee Self Ser... UI Libraries ACHNC Iowa's Public Heal... Regions 4 Login Box-Tarin ILL 42 U.S. Code § 3...

Home Contact Login/Logout Custom Search Search Calendar IT Jobs@SHL

About the SHL Education/Training Lab Certification Publications News

State Hygienic Laboratory
at The University of Iowa

Director Christopher Ashton greets the members of the IA Hygiene Association who toured the Laboratory.

Test Results

- Test Results
- Clinical Test Request Forms
- A-Z Test Menu

Environmental

- Test Menu
- Air Quality
- Analytical Services
- Grants to Counties
- Well Water
- Surface Water

Newborn & Maternal Screening

- Abnormalities
- Disorders
- Maternal Screening
- Newborn Screening

Disease Control

- Test Menu
- Test Request Forms
- Microbiology
- Influenza
- Molecular Diagnostics
- Serology

Center for the Advancement of Laboratory Science

- Explore
- Learn
- Engage
- Partners

Videos

- Meet our Student Mentor!
- What is a Public Health Laboratory?
- Putting Babies First through Newborn Screening
- Baby's First Test

What's Popular?

- Hourly Air Quality Index Maps


News

Shigellosis sickens more than 560
A Shigellosis outbreak in the state has sickened more than 560 people from about March 1 to Dec. 18. Shigellosis is a gastrointestinal disease caused by Shigella bacteria that can be spread by person-to-person contact or by infected food.

Goldfinch flies into Winter Games
The American goldfinch, Iowa's state bird, will be the image created on the ice in front of Lakeside Lab - Regents Resource Center for the ninth annual Winter Games of the Midwest.

Connect

State Hygienic Laboratory
December 31, 2015 at 9:40am
Wonder how this influenza season compares to last year's? Our Dr. Wendy Atkinson explains the CDC's...




State Hygienic Laboratory

at The University of Iowa

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TEST RESULTS


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OpenELIS


Neonatal Screening


PHIMS


ELIS

Questions about web access may be directed to ask-shl@uiowa.edu or to 319.335.4358.

OpenELIS

The Open Enterprise Laboratory Information System (OpenELIS) web portal contains results for environmental, safe drinking water, and private well samples received at SHL beginning on Jan. 1, 2012, and clinical samples (except for rabies, maternal screening and newborn screening) received at SHL beginning on March 1, 2015.

Neonatal Screening

The Neonatal Metabolic Screening Program web portal contains newborn screening test results and provides follow-up capabilities.

PHIMS

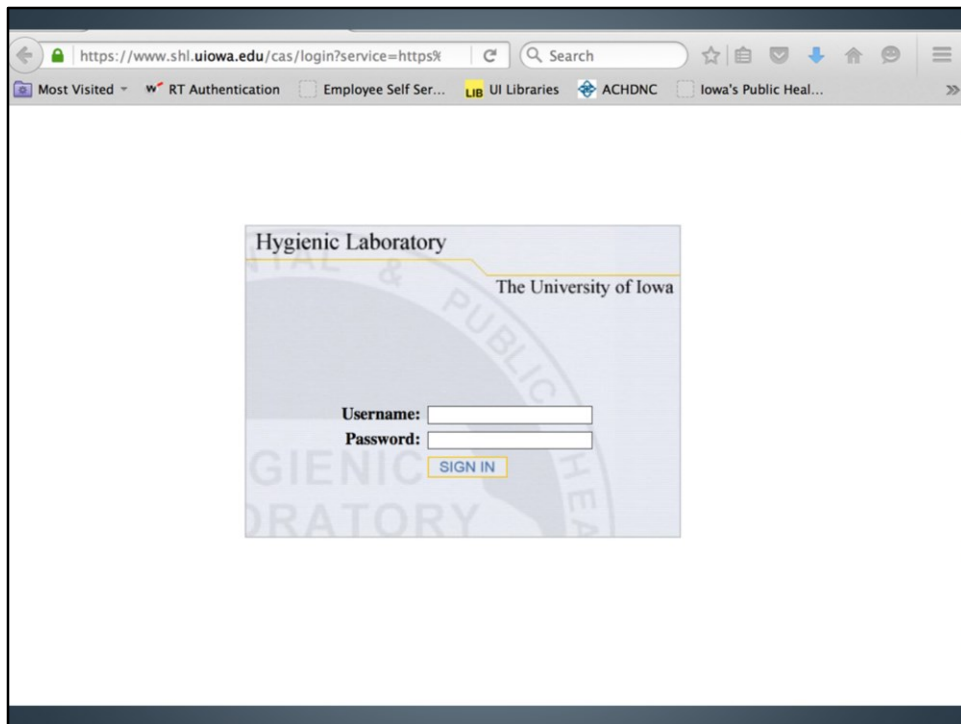
The Public Health Information Management System web portal contains all test results for clinical samples received at SHL before March 1, 2015, and for rabies and maternal screening results until this testing is transitioned into the OpenELIS web portal.

Forms

- Results Web Access
- Paperless Results Reporting
- Faxed Results Reporting

Web Portal User Guides

- OpenELIS
- PHIMS
- Neonatal Screening
- Change Password



<https://www.shl.uiowa.edu/nmsp/Facility>
Search

Most Visited
RT Authentication
Employee Self Ser...
UI Libraries
ACHDNC
Iowa's Public Heal...



STATE HYGIENIC LABORATORY

AT THE UNIVERSITY OF IOWA

[Change Password](#)
[Log Out](#)

Patient Lookup

Gender

Birth From

Birth To

Id #

Chart Number

Lab Number

Run
Reset

Patient	Birth	Facility	Patients Gender	Lab No.	Collection
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Download Reports

Samples Received

Quality Control

Turnaround Statistics

Facility Summary



[Change Password](#) | [Log Out](#)

[Patient Lookup](#)

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[Turnaround Statistics](#)

Beginning Collected 2015-12-01



Ending Collected 2015-12-31



Sort Order Birth to Received



[Run](#) [Reset](#)

[Facility Summary](#)

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Jan 08, 2016
14:12:16

Sample Turnaround Report
From 2015-12-01 to 2015-12-31

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web

Facility Name

Patient Name	Chart Number	Repeat	Birth to Collection	Collection to Receive	Birth to Receive	Receive to Report	Birth to Report
			23	43	71	27	4 d 2 h
			24	46	71	23	4 d 1 h
			32	49	81	29	4 d 15 h
			39	48	87	25	4 d 17 h
			34	64	90	29	5 d 0 h
			24	88	112	25	5 d 17 h
			27	91	119	31	6 d 0 h
			24	94	120	25	6 d 2 h
			30	97	127	25	6 d 8 h
			30	97	128	25	6 d 10 h
			24	107	131	31	6 d 19 h
			24	108	133	31	6 d 21 h
		X	289	90	289	25	13 d 13 h
Total Samples 13			Average Turnaround Time (# of samples for averages)				
			27(12)	78(12)	90(12)	27(12)	5 d 14 h

Note: Repeat specimens, specimens with dates missing and specimens collected greater than 3 days after birth are not used for determining averages. Times are in hours except for "Birth to Report" which is in days and hours.

This shows a sample data report with turnaround metrics. (not the same facility as the infographic)

The patient's names and medical chart numbers have been blacked out. The report indicates the time period of the report, the name of the facility (which is blacked out on this sample report) and the date the report was run.

Metrics that are included in the Turnaround report:

Whether the specimen was a repeat specimen or not (only initial specimens are included in the timeliness measure)

The time span (in hours) between birth and collection of the specimen

The time span (in hours) between when the specimen was collected and when it was received by the SHL

The time span (in hours) between birth and when the specimen was received by the SHL (**the CoIN metric**)

The time span (in hours) between when the specimen was received by SHL and when results were reported

The time span (in days and hours) between birth and when results were reported

Additional Resources

- Listserv – Listserv maintained by CCID. Can include anyone. Right now goes to NBS partners – labs, clinical, some providers. Anyone can reply or post a message to the listserv
- INSP staff – Use us!
- COLLN Team – Great resource for COLLN info
- Each other – You are the experts

INSP Lead Staff and ColIN Members

- Kim Piper Kimberly.piper@idph.iowa.gov
- Carol Johnson Carol-Johnson@uiowa.edu
- Stan Berberich Stanton-Berberich@uiowa.edu
- Ashley Comer Ashley-Comer@uiowa.edu
- Kristin Ernsperger
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- Jennifer Nutt nuttj@ihaonline.org
- Kimberly VonAhsen
Kimberly.VonAhsen@unitypoint.org

PARTNER DISCUSSION

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We would like to open it up to all of you for discussion. We have representatives from hospitals that were in the pilot project as well as others who have already been working on this initiative.